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**The cancer care experiences of gay, lesbian and bisexual patients: A secondary analysis of data from the UK Cancer Patient Experience Survey.**

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**Short title:** Sexual orientation differences in cancer care

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**Abstract**

Understanding the effects of population diversity on cancer-related experiences is a priority in oncology care. Previous research demonstrates inequalities arising from variation in age, gender and ethnicity. Inequalities and sexual orientation remain underexplored. Here, we report, for the first time in the UK, a quantitative secondary analysis of the 2013 UK National Cancer Patient Experience Survey which contains 70 questions on specific aspects of care, and six on overall care experiences. 68,737 individuals responded, of whom 0.8% identified as lesbian, gay or bisexual. Controlling for age, gender and concurrent mental health comorbidity, logistic regression models applying post-estimate probability Wald tests explored response differences between heterosexual, bisexual and lesbian/gay respondents. Significant differences were found for 16 questions relating to: (a) a lack of patient-centred care and involvement in decision making, (b) a need for health professional training and revision of information resources to negate the effects of heteronormativity, and (c) evidence of substantial social isolation through cancer. These findings suggest a pattern of inequality, with less positive cancer experiences reported by lesbian, gay and (especially) bisexual respondents. Poor patient-professional communication and heteronormativity in the healthcare setting potentially explain many of the differences found. Social isolation is problematic for this group and warrants further exploration.

**Keywords:** Cancer, Oncology, Health Surveys, Equality, Sexual Orientation, Patient Experience

## Introduction

Across all aspects of cancer care, there is an important drive to explore the effects of population diversity. Recent work has demonstrated inequalities in the patient-reported experience arising from variation in age, gender (Din et al, 2015) and ethnicity (Naylor, Ward & Polite, 2012). Far less is known about the impact of sexual orientation on cancer care experiences (Quinn et al 2015). The differential experiences of lesbian, gay and bisexual (LGB) cancer patients is important to understand, not least because this group is at increased risk of specific cancers. Pre-menopausal lesbian and bisexual women have higher risk of breast, cervical, ovarian and lung cancers compared to heterosexual women (Boehmer et al, 2012; Clavelle et al, 2015) and gay men are at increased risk of anal cancer beyond that risk observed in heterosexual men (Chin-Hong et al, 2005; Goldstone et al, 2011). Overall, gay men are reported to be 1.9 times more likely to have cancer over their lifetime compared with heterosexual men (Boehmer, Miao & Ozonoff, 2011). Much of this increased risk is likely due to lifestyle and health behaviour factors, such as alcohol use and smoking (Hagger-Johnson et al, 2013).

Sexual orientation data is not routinely collected in either clinical practice or research (Kamen et al, 2015): this results in very little knowledge about how sexuality impacts cancer outcomes or experiences of care. A recent scoping review (Semlyen & Hulbert-Williams, 2013) summarised existing literature demonstrating that LGB patients, when compared to heterosexuals, report poorer quality of life, anxiety and depression (Boehmer et al, 2011; Boehmer, Glickman & Winter, 2012) and more negative experiences of care and support during treatment (Matthews et al, 2012) but found a dearth of information on experiences of survivorship care. A more recent study partly addresses cancer survivorship, reporting a disparity in psychological distress in gay men compared to heterosexual men (Kamen et al, 2014). The majority of current knowledge focuses on lesbian or gay people's experiences of cancer, and few studies explore the needs or experiences of bisexual patients; whether this results from a lack of dedicated funding, insufficient expertise or interest within oncology research, or that previous attempts to undertake work with bisexual patients has failed to produce publishable results (for example, failure to identify and recruit sufficient participant numbers) is unclear. Regardless, comparative research of the experiences of all groups of sexual orientation is essential to identify and address cancer care inequality.

Large scale research in this area is sparse and secondary analysis of large datasets may be useful. One recent example of this describes sexual orientation inequality in psychological distress resulting from cancer in a large US dataset (Kamen et al, 2015). The authors highlight important differences in distress based on the intersection of sexual orientation and gender, and that differences in support perceived as being available to different demographic sub-sets of patients may be an overall explanatory factor in predicting distress levels.

The UK National Cancer Patient Experience Survey (NCPES<sup>1</sup>) lends itself to a similar secondary analysis of UK cancer experiences. Distributed annually to patients who receive cancer treatment in the UK, results are used to explore service provision differences and track quality improvement over time. Although differences in relation to sexual orientation were initially explored in the 2013 National Report (Quality Health, 2013) this did not statistically control for potentially confounding variables and grouped participants in such a way that makes interpretation of results difficult.

This paper reports a more rigorous secondary analysis of the 2013 NCPES data, aiming to understand how the experiences of LGB patients with cancer differ from those of heterosexual patients. There are inherent problems with using secondary data, most notably including the small numbers identifying as LGB, and issues pertaining to the wording of specific questions: these will be discussed in detail later in this paper. The NCPES is, however, the largest dataset of cancer experience that enables analysis of this type and despite methodological and sampling limitations thus provides a valuable resource for exploratory analysis in this under-researched field. We adopt an epistemologically explorative stance; our intention is to highlight areas of potential inequality to inform future research. This analysis is the first of its kind within the UK cancer context.

## Methods

The NCPES contains 72 self-report questions about cancer care: 66 focus on specific areas of care (e.g. interaction with healthcare professionals, provision of information etc.) and six focus on overall experiences. Nine demographic questions are asked, including one on sexual orientation. The survey was conducted by Quality Health and responses are matched to electronic hospital records for accurate clinical information. We used data from the 2013 survey: this was sent out to patients who received cancer treatment between 1<sup>st</sup> September and 20<sup>th</sup> November 2012. Ethical approval for the original survey (including later secondary uses of the data) was obtained by Quality Health from the Ethics and Confidentiality Committee of the National Information Governance Board (Ref: ECC 6-02(FT4)/2012). Data from the survey were deposited to the UK Data Service under End User Licence (EUL) Conditions (Department of Health, 2013); following registration with the UK Data Service we were permitted to download the data for secondary analysis.

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<sup>1</sup> Readers wishing to know more about development and administration of the NCPES are referred to the Quality Health website: <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

## Participants

The 68,737 survey respondents represented a 64% response rate. 53% were female, 63% were retired, and their mean age was 66.3 years (SD=12.36). 96% identified as white-British indicating under representation of black and minority ethnic populations. 66% of respondents were within the first year since diagnosis. Although all cancer sites were represented, 49% were diagnosed with one of the four most common cancers in the UK (breast, colorectal/lower gastro-intestinal, prostate, lung).

Sexual orientation was determined by response to the question “Which of the following best describes your sexual orientation?”. 89.3% of respondents identified as *heterosexual/straight*; 425 (0.6%) identified as *lesbian or gay*; 143 (0.2%) identified as *bisexual*; 0.9% of respondents chose ‘*other*’; and 3% indicated a *preference not to answer*. A further 6% left the question blank. The small numbers identifying as LGB are unlikely to represent accurate population proportions of these sexual identities in the UK. The British National Survey of Sexual Attitudes and Lifestyles (NATSAL) for example, reported that 2.5% of men, and 2.4% of women self-identify as LGB, and an increasing number of both men and women report engaging in same-sex sexual behaviour (Mercer et al, 2013). Though we can only speculate on reasons for this, it is likely that this reflects an ongoing unwillingness to disclose sexual orientation in the context of the NCPES, which is compounded by the older mean age of the overall sample. A full sociodemographic and clinical comparison table of respondents to the NCPES used for this secondary analysis can be viewed in table 1.

\*\*\*INSERT TABLE 1 ABOUT HERE\*\*\*

## Analysis

Sexual orientation was operationalised as three categories: heterosexual, bisexual, and lesbian/gay. Though an argument could be made to group the participants differently, our choice was informed by three considerations. First, it allowed a cleaner disambiguation between gender and sexual orientation: had we, for example, analysed lesbian and gay respondents separately we would not necessarily know whether the differences were a result of sexual orientation or gender differences unless we had also split the heterosexual and bisexual group in the same way. With such low participant numbers in the LGB groups already, further fragmentation would have reduced statistical power and increased the potential for Type I error; this was our second consideration. Instead, a more statistically rigorous approach was to test and control for the confounding effects of gender (and other demographic variables) across the entire sample; had we split the lesbian and gay group by gender *and* made a gender-based statistical control, we would be

accounting for the effects of gender twice in some participant groups, but only once in the others which would be inappropriate. Power could have been increased further by merging lesbian, gay and bisexual into one category, however we had no strong *a priori* reasoning for assuming the experiences of bisexual and lesbian and gay participants would be similar enough to be grouped in this way; indeed, our results support this decision by finding clear differences between the two groups. Finally, it maintained participant grouping as defined by the participants themselves in response to the sexual orientation question on the survey.

Those who responded 'other' or who indicated a preference not to answer were not included in the analysis. Whilst no explicit assumption is made about the type of missing data, it is unlikely that it occurs randomly in all cases; we thus did not impute sexuality to avoid adding bias.

Multinomial logistic regression (with sexual orientation as the dependent variable) was used to identify socio-demographic and clinical confounders. Gender, age, and concurrent mental health comorbidity were each statistically significant in predicting the likelihood of sexual orientation (three categories: heterosexual, lesbian and gay, bisexual), and so were selected as independent variables for later analyses. Level of education, ethnicity and physical health co-morbidities were not significant and so were not included in the later analyses. We were unable to account for differences in cancer type or treatment due to small sub-group sizes in the lesbian/gay and bisexual groups.

Logistic regression analyses were performed for each question with sexual orientation, gender, age and concurrent mental health comorbidity forced into each model as independent variables. Questions with multiple response options were analysed using ordinal or multinomial logistic regression, depending on whether categories had a natural ordering. The significance of differences in response by category of sexual orientation were explored, applying post-estimation probabilities using Wald tests. Wald tests are based upon the estimated variance-covariance matrix of estimators and are asymptotically equivalent to likelihood ratio tests. However, they have the advantage of requiring only one model, thus offering a pragmatic alternative in the case of multiple analyses (Long & Freese, 2006). Analyses were performed in Stata 13.

We explored differences in responses to all questions except for question 66 (Have you had treatment from any of the following for your cancer? Response options: physiotherapist, occupational therapist, dietician, speech and language therapist, lymphoedema specialist) as data here was recorded only if patients answered in the affirmative. As a result, positive response rates varied considerably (9% to 38%) across each category. It is unsafe to assume that where participants left this question blank that this corresponded to a negative response, and as such the data could not be considered robust.

We employed an exploratory rather than hypotheses-driven approach to analysis (Grove & Andreasen, 1982) adopting a standard alpha level of 0.05 for statistical significance, but without making any adjustment (e.g. Bonferroni Correction) for multiple testing; such corrections are used to reduce probability of Type I error but as we had no *a priori* hypotheses this was not relevant to our study aim.

## Results

Complete data was available for sexual orientation and control variables for 57,402 respondents; the remaining 16% of participants were excluded from this analysis. In 16 of 69 questions analysed, sexual orientation was a significant predictor of response (at  $p < 0.05$ ). These are summarised in Table 2; this should be cross-referenced with Figure 1 which shows between-group comparison.

\*\*\*INSERT TABLE 2 ABOUT HERE\*\*\*

Wald test results indicate for which questions an overall significant difference in response exists across categories of sexual orientation – statistical significance for these tests is included in parentheses in the summary of results which follows. For these questions we explored post-estimation probabilities of differences between each sexual orientation category (see Figure 1). Below, we report on questions in which post-estimation results for sexual orientation categories were significant ( $p < 0.05$ ; for full results, see supplementary material.)

\*\*\*INSERT FIGURE 1 ABOUT HERE\*\*\*

### *Questions about cancer diagnosis*

Bisexual respondents were significantly less likely to report that they had had a diagnostic test for cancer within the previous 12 months ( $p = .03$ ). They were also more likely to respond that they were told by a nurse or other healthcare professional (than a doctor) that they had cancer, and significantly less likely to have received this information through lay-referral (via friend or relative) than other sexual orientation participant categories ( $p = .03$ ). When asked whether they had been given any written information at diagnosis, bisexual respondents were more likely to respond “Yes, but it was difficult to understand” ( $p = .01$ ).

### *Questions about treatment decisions*



Bisexual respondents were more likely to report that they would have liked a choice of treatment option but were not offered one, and lesbian/gay respondents more frequently responded that that were not given a choice because there was only one suitable treatment type available ( $p<.01$ ). Bisexual respondents reported that they were not as involved as much as they would have liked to have been in decisions about their care and treatment ( $p<.01$ ), and that they were not given written information about side-effects of treatments; lesbian/gay respondents more frequently responded that they received this information, but that it was difficult to understand ( $p=.01$ ).

#### *Questions about relationships with healthcare professionals*

When asked about their relationships with healthcare professionals, bisexual respondents were more likely to indicate that it was difficult to contact their nurse specialist ( $p<.01$ ), and that they got understandable answers to important questions only “some of the time” ( $p=.01$ ). A higher proportion of bisexual respondents indicated that ward nurses talked in front of them as if they were not there ( $p=.02$ ). In response to the question “If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?”, a higher proportion of both lesbian/gay and bisexual respondents indicated that either no family or friends were involved, or that they did not *want* their family or friends involved, compared with heterosexual respondents ( $p<.01$ ). That is, the difference was not one of a lack of opportunity provided to talk to doctors but rather that there wasn’t a significant person involved to take up such opportunity.

#### *Questions about care after treatment had finished*

During aftercare, bisexual respondents were less likely to report they had been given enough care and help from health and social services ( $p=.03$ ), and reported that hospital staff did everything possible to control radiotherapy side effects, “only to some extent” ( $p=.05$ ). Lesbian/gay respondents were less likely than both heterosexuals and bisexuals to have received a written care or assessment plan ( $p=.02$ ). Once again, when asked whether family or those close to them were given all the information they required regarding home care, LGB respondents were more likely to have replied that either no family or friends were involved, or that they did not want their family or friends involved ( $p<.01$ ).

#### *Questions about psychosocial support and overall care*

Lesbian/gay respondents were more likely to indicate that they were not treated with dignity and respect through their cancer care ( $p=.01$ ). When asked whether they felt that they were treated as “a set of symptoms” rather than a whole person, bisexual respondents were more likely to respond “yes, often” ( $p=.01$ ).

## Discussion

This study offers an important contribution to understanding the cancer experiences of a marginalised socio-demographic group. In undertaking a large-scale secondary analysis of a substantial nationally-administered survey of cancer patient experiences, we build on the findings reported by Kamen et al (2015); secondary analysis of this type ensures that our findings are not limited by design considerations or specific sociodemographic or clinical inclusion criteria.

### *Contextualising the findings*

Provision and utilization of healthcare services amongst LGB people are affected by the specific legislative and socio-cultural framework in each country (Quinn et al, 2015). Given recent changes in the landscape for sexual equality in the UK (for example the inclusion of sexual orientation in equality and discrimination legislature (Equality Act, 2010) and the introduction of the Civil Partnership Act (2004) and so forth), it is both timely, and useful to explore potential inequality in cancer experiences in a UK sample. Despite the UK focus of our data, many findings have global implications, and are relevant especially in the context of the International Psycho-Oncology Society (IPOS) Lisbon Declaration (IPOS, 2014) which advocates quality psychosocial oncology care as a fundamental human right for all; empirical research that identifies and addresses inequality is essential achieving this goal.

Consistent with broader literature (Boehmer et al, 2011; Kamen et al, 2015; Boehmer et al, 2012; Kamen et al, 2014), our findings suggest a pattern of inequalities in cancer care for LGB people, though where earlier studies focus on patient-reported outcome measures (e.g distress), ours focus on healthcare experiences; the findings are thus complementary and broaden our understanding of diversity in cancer care. This was especially true for bisexual respondents, a finding not so explicitly evident in previous research. For lesbian/gay respondents, specific aspects of care were often equivalent to heterosexual respondents. However, the experiences of lesbian and gay respondents mirror bisexual respondents on key themes related to patient-centred care provision and social isolation, each of which remain of concern.

The patterning of responses to the sexual orientation question on the NCPES highlight difficulties with the disclosure of sexual orientation This is likely to be reflected in face to face disclosure within healthcare consultations. Disclosing sexual orientation to healthcare providers is stressful (Kamen et al, 2015) and can result from perceptions of heteronormativity and heterosexism (Irwin, 2007; Meyer, 2003), stigmatization (Whitehead, Shaver & Stephenson, 2015), discrimination (Elliott et al, 2015; Quinn et al, 2015), fears of substandard treatment (Boehmer & Case, 2004), poor treatment of same-sex partners (Barbara, Quandt & Anderson, 2001), and heterosexist assumptions of sexual orientation (Hinchliff, Gott & Galena, 2005; Neville & Henrickson, 2006). This can affect numerous aspects of engagement and

satisfaction with healthcare including utilization of services (Whitehead, Shaver & Stephenson, 2015), and poor communication (Morrison & Dinkel, 2012).

Responses to the NCPES indicated a substantially greater number of significant differences in perception of cancer care experiences for bisexual respondents; greater even than for those identifying as lesbian or gay. Discrimination toward bisexual people (and indeed transsexual/ transgender communities) compared with lesbian and gay people in the UK has been slower to improve; marginalization comes from multiple sources, including from within the lesbian/gay community (Clarke et al, 2010). We postulate that a greater number of negative cancer care experiences reported by this group may be a consequence of this continued inequality, and lack of acceptance and understanding by wider society. Health issues such as cancer, may produce additional burden onto this already vulnerable group, and this needs to be better understood to enable intervention and service provision to adequately address these differences.

Of course, there remains the possibility that the differences in experiences identified in this study are caused by unmeasured, tertiary variables. It is in some cases difficult to reconcile, for example, the extent of differences observed for a non-disclosing bisexual cancer patients who may attend clinic with an opposite-sex partner. Even though in this case there may be no explicit *prompt* to disclose sexual orientation to a healthcare provider, there is indeed an implicit *need* to do so in order to ensure optimal patient-centred communication and care. The unwillingness to disclose on the part of the patient (as discussed above), combined with a lack of sexual orientation monitoring and questioning on the part of the healthcare provider, may well act as a substantial barrier to disclosure. Future research is clearly required to more fully explain differences in cancer experiences between those identifying as lesbian, gay and bisexual.

Our specific findings orient around three central themes:

### *1. Patient-centred care and shared decision making*

Bisexual respondents were significantly more likely to have reported that they were informed about their diagnosis by a nurse or other healthcare professional, but thereafter to have found it difficult to contact nurse specialists and to get understandable answers from them. They similarly reported that they were dissatisfied with their interaction with nurses on hospital wards, and the care and help provided by both health and social care services after leaving hospital. With a focus on patient-centred holistic care, the nursing workforce remains one of the most important sources of support and care for cancer patients (Hulbert-Williams, 2016); previous research has demonstrated that nurse-led psychosocial care reduces distress (Lewis et al, 2009), and provides an effective model of follow-care (Swanson & Koch, 2010). That this wasn't the case for bisexual respondents in this survey is

surprising and necessitates further empirical attention; this should be prioritised in future research.

Despite wanting to be more involved in treatment decision-making, bisexual respondents indicated that they were not given a choice of treatments; similarly, lesbian/gay respondents indicated that they were informed that a choice of treatment was not available to them. This is an important finding given the global recognition of the importance of patient (and friends/family's) involvement in healthcare decision-making. Irwin suggests that this discrepancy exists for LGB people as a direct result of homophobia and heterosexism (Irwin, 2007) but does not offer a causal explanation. Our findings confirm the continuation of these inequalities in the UK cancer care context.

## *2. Implicit inequality via heteronormativity in information provision*

LGB respondents significantly differed from heterosexual respondents in their satisfaction with written information provided at diagnosis, treatment and aftercare. Broader literature suggests that perceived discrimination can arise where outward behaviour does not differ, but instead by omission. Typical communication strategies and information resources, whilst not explicitly homophobic, can perpetuate heteronormativity. Conversational micro-cues (Kitzinger, 2005a; Kitzinger, 2005b) and an over-reliance on heterosexual imagery (Blank, 2005), can create an implicit exclusionary context, leading to low levels of satisfaction. Sexual orientation equality is not necessarily about treating all people the same, but matching care to individual needs for all patients *regardless of sexual orientation* (Quinn et al, 2015), and this doesn't seem to have been the case with respect to these specific cancer care experiences.

## *3. Social Isolation*

This tacit exclusionary context becomes more problematic when considering that LGB respondents either do not have, or are choosing to exclude, significant others from their cancer experience. It is unfortunate that the survey didn't include a question on relationship status as this may have helped to further understand responses to these questions and to better contextualise the findings against Kamen et al's US data (Kamen et al, 2015). This finding is not unique to cancer care—for LGB patients with dementia, the main source of informal care is not usually provided by family, with reliance instead on friends (Peel & McDaid, 2015)—and has been explained elsewhere as a deliberate strategy to protect family and friends from negative consequences of homophobia and heteronormativity (Barbara, Quandt & Anderson, 2001); the same may well be true in the cancer context. All patients should be entitled to choose the degree of involvement of their loved ones (friends or family) in their care, but if that process involves sexual orientation disclosure, it is possible that choosing to exclude them may be regarded as a safer option. This

paints a worrying picture of continued social isolation through cancer as previously reported (Grossman, D'Augelli & Hershberger, 2000).

### *Study evaluation*

There are limitations to our analyses, many of which are common to secondary analysis methodology. First, findings are based on only a small and disproportionate sub-sample of those identifying as LGB. Whilst gender has been identified as an important covariate in understanding sexual orientation cancer care experience (Kamen et al, 2015), we chose to maintain lesbian and gay respondents as a single category (statistically controlling for gender effects); this method not only matched the response options from the original survey but also increased statistical power for comparison analysis. However in doing so we admittedly lose the distinct experiences of these discrete groups.

Not including bisexual and 'other' respondents into this same category reflects a pragmatic attempt to minimise further dilution of findings. Whilst there were sufficient numbers to gain meaningful insight into the experiences of bisexual respondents, the group size for the 'other' category was too small for analysis. Choosing 'other' is, however, a meaningful response choice (rather than "prefer not to say"): it suggests a sexual orientation that cannot neatly be defined by heterosexual, gay, lesbian or bisexual (for example asexual, pansexual, sexually fluid and so forth). A recent publication reports that levels of common mental disorder symptoms (e.g. depression, anxiety) in individuals identifying as 'other' are more similar to those identifying as LGB than they are to heterosexuals (Semlyen et al, 2016). It is reasonable to ask, therefore, whether this shared non-heterosexual identity will impact on other aspects of life, and whether their cancer care experiences too may be poorer than those of heterosexual respondents. There is clearly more work to be done on understanding the cancer care experiences in those identifying as non-heterosexual or LGB, thus highlighting a further important question for future research.

Similarly, missing sexual orientation data was problematic: other studies have suggested that LGB people more often refuse to disclose sexual orientation (Ellison & Gunstone, 2009) and so the high proportion of missing data here is likely representative of the experiences of a broader group of non-disclosing LGB cancer patients. The combined effects of missing data on sexual orientation *and* statistical control variables resulted in 16% respondent exclusion which is an unavoidable limitation. If we were to make recommendations for future iterations of the NCPES, we would suggest that response options to the question on sexual orientation be reconsidered to ensure that the data gathered is both more meaningful and usable in data analysis.

A particular strength of our study is that we did not limit our analysis to a particular sociodemographic or clinical subgroup. We undertook a statistically robust approach

to identifying sociodemographic and clinical confounding variables (ruling out some expected confounders, such as ethnicity (Naylor, Ward & Polite, 2012)) and we corrected for these as appropriate in comparative analysis. This is especially important in the case of age; older LGB individuals are likely to have a longer history of experiencing homophobia than younger generations. This is likely to affect interaction with healthcare professionals which in turn may have affected care experiences.

Specific wording of some questions is problematic but something we had little control over; whilst it is important to consider the findings with appropriate caution we do not think this undermines the key findings from our work—our aim was exploratory and in that context we identify important areas of future study. We nonetheless urge those who may replicate this survey to consider nuanced language: some questions have ambiguous and vague wording; others, for example the question about time to first appointment, are not compliant with good practice guidelines (in this case, the Aarhus Statement (Weller et al, 2012)). There are known differences between self-reported sexual orientation and sexual practice (Mercer et al, 2013) and so asking about sexual attraction and behaviour would be useful (Joloza et al, 2010) as would directly asking whether respondents feel that their sexual orientation impacted on cancer experiences.

Finally, it is important to note that this work undertakes a secondary analysis of health service evaluation questionnaire rather than any validated psychometric tools. As such it has not been exposed to rigorous validity testing. We would caution readers to bear this in mind when considering the implications of the findings.

### *Implications of the findings*

Retrospective self-report data has multiple methodological pitfalls. Not least, survey questions ask about what individuals remember and report, not what actually *happened*. It may be that there was no real difference in the care and support provided to LGB patients, but that they remember or evaluate it somehow differently, for known or unknown reasons. Even if the differences are perceptual rather than behavioural, however, this may indicate a lack of bi-directional understanding between patient and healthcare professionals, and that has important clinical implications. In the context of the varied range of differences found in this analysis, it is understandable why lesbian/gay and bisexual respondents differed in their perceptions of how much they were treated with “dignity and respect”, and “as a set of symptoms rather than a whole person”.

These differences may relate to communication (both direct and implicit; written and verbal) between patients and healthcare teams. More explicit opportunity is needed to facilitate disclosure of sexual orientation to lower consequent burden during times of crisis, such as cancer diagnosis (Boehmer & Case, 2004). This perceived burden can be reduced with approaches that reduce perceptions of heteronormativity and

implicit discrimination. Previous research advocates a need for more training to support healthcare professionals in providing cancer care to sexual minority groups (Kamen et al, 2015; Reygan & D'Alton, 2013), and our findings add further weight to this. Such training may be beneficial in creating an environment in which comfortable communication exists (Klitzman & Greenberg, 2002) and where psychosocial support needs can be understood and met (Hinchliff, Gott & Galena, 2005). Furthering opportunities to acknowledge and discuss non-normative family dynamics and more inclusionary practice toward the acceptability of non-traditional modes of caring and support should be recognised, and may provide appropriate outcomes for staff training and development (Harding, Epiphaniou & Chidgley-Clark, 2012).

Efforts to standardise monitoring of sexual orientation within healthcare and research are important to enable on-going analysis of, and opportunities to address, health inequalities (Kamen et al, 2015). On the basis of this study, and where it sits within a broader context of LGB research in cancer, a number of questions still remain. A programme of mixed methods, interdisciplinary research is needed to empirically examine the varied issues raised within this paper.

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**Table 1: Summary sociodemographic and clinical description for heterosexual, lesbian/gay and bisexual sub-samples**

|                            | Heterosexual<br>(N = 61,398) | Lesbian/Gay<br>(N = 425) | Bisexual<br>(N = 143) |
|----------------------------|------------------------------|--------------------------|-----------------------|
| Age Mean (SD)              | 66 (12.3)                    | 57.5 (13.4)              | 64 (14.9)             |
| Gender N (%)               |                              |                          |                       |
| Female                     | 32,485 (52.9)                | 173 (40.7)               | 62 (43.4)             |
| Male                       | 28,913 (47.1)                | 252 (59.3)               | 81 (56.6)             |
| Ethnicity N (%)            |                              |                          |                       |
| British / Irish            | 57,342 (99.1)                | 379 (0.7)                | 121 (0.2)             |
| Other White                | 1,118 (97.9)                 | 20 (1.8)                 | 4 (0.35)              |
| Other                      | 2,174 (98.7)                 | 18 (0.8)                 | 11 (0.5)              |
| Time since diagnosis N (%) |                              |                          |                       |
| < 1 year                   | 40,051 (66.2)                | 286 (67.8)               | 83 (61)               |
| 1-5 years                  | 15,128 (25.0)                | 112 (26.5)               | 37 (27)               |
| > 5 years                  | 5,138 (8.5)                  | 24 (5.7)                 | 15 (11.0)             |
| Don't know/ can't remember | 165 (0.3)                    | 0 (0.0)                  | 2 (1.5)               |
| Employment N (%)           |                              |                          |                       |
| Full time                  | 10,299 (17.0)                | 142 (33.7)               | 30 (21.3)             |
| Part time                  | 5,566 (9.2)                  | 38 (9.0)                 | 17 (12.1)             |
| Homemaker                  | 1,698 (2.8)                  | 4 (1.0)                  | 3 (2.1)               |
| Student                    | 162 (0.3)                    | 6 (1.4)                  | 1 (0.7)               |
| Retired                    | 37,740 (62.4)                | 148 (35.1)               | 72 (51.1)             |
| Unemployed (seeking)       | 414 (0.7)                    | 9 (2.1)                  | 1 (0.7)               |
| Unemployed (health)        | 3,392 (5.6)                  | 60 (14.2)                | 12 (8.5)              |
| Other                      | 1,263 (2.1)                  | 15 (3.6)                 | 5 (3.6)               |
| Comorbidities N            |                              |                          |                       |
| Deafness                   | 6,267 (10.9)                 | 32 (8.0)                 | 19 (14.0)             |
| Blindness                  | 1,378 (2.39)                 | 3 (0.8)                  | 3 (2.2)               |
| Physical disability        | 8,329 (14.5)                 | 53 (13.2)                | 21 (15.4)             |
| Learning disability        | 222 (0.39)                   | 2 (0.5)                  | 2 (1.5)               |
| Mental health              | 1,188 (2.06)                 | 33 (8.2)                 | 8 (5.9)               |
| Long standing illness      | 8,108 (14.1)                 | 74 (18.5)                | 22 (16.2)             |
| None                       | 37,455 (65.1)                | 244 (61.0)               | 76 (55.9)             |
| Comorbidities Mean (SD)    | 0.4427 (0.6681)              | 0.4913 (0.6786)          | 0.5515 (0.6973)       |
| Ethnicity N (%)            |                              |                          |                       |
| British                    | 56,524 (93.2)                | 370 (88.7)               | 117 (86.0)            |
| Irish                      | 818 (1.4)                    | 9 (2.2)                  | 4 (2.9)               |
| Other White                | 1,118 (1.8)                  | 20 (4.8)                 | 4 (2.9)               |
| White & Black Caribbean    | 77 (0.1)                     | 2 (0.5)                  | 1 (0.7)               |
| White & Black African      | 29 (0.1)                     | 2 (0.5)                  | 0 (0.0)               |
| White & Asian              | 86 (0.1)                     | 0 (0.0)                  | 0 (0.0)               |
| Other mixed                | 70 (0.1)                     | 4 (0.1)                  | 1 (0.7)               |
| Asian                      | 477 (0.8)                    | 2 (0.5)                  | 4 (2.9)               |
| Pakistani                  | 179 (0.3)                    | 1 (0.2)                  | 1 (0.7)               |
| Bangladeshi                | 49 (0.1)                     | 0 (0.0)                  | 0 (0.0)               |
| Other Asian                | 205 (0.3)                    | 1 (0.2)                  | 1 (0.7)               |
| Caribbean                  | 438 (0.7)                    | 3 (0.7)                  | 1 (0.7)               |
| African                    | 286 (0.5)                    | 1 (0.2)                  | 2 (1.5)               |

Sexual orientation differences in cancer care

|              |                                     |           |         |         |
|--------------|-------------------------------------|-----------|---------|---------|
|              | Other black                         | 35 (0.1)  | 0 (0.0) | 0 (0.0) |
|              | Chinese                             | 151 (0.3) | 1 (0.2) | 0 (0.0) |
|              | Other                               | 92 (0.2)  | 1 (0.2) | 0 (0.0) |
| Tumour Group |                                     |           |         |         |
|              | Brain/Central Nervous System        | 663       | 2       | 7       |
|              | Breast                              | 12,601    | 23      | 71      |
|              | Colorectal / Lower Gastrointestinal | 7,894     | 14      | 61      |
|              | Gynaecological                      | 3,436     | 8       | 26      |
|              | Haematological                      | 10,341    | 35      | 73      |
|              | Head and Neck                       | 2,177     | 7       | 18      |
|              | Lung                                | 4,431     | 4       | 29      |
|              | Other                               | 2,465     | 3       | 17      |
|              | Prostate                            | 5,045     | 18      | 38      |
|              | Sarcoma                             | 629       | 0       | 14      |
|              | Skin                                | 1,662     | 4       | 11      |
|              | Upper Gastrointestinal              | 3,834     | 8       | 28      |
|              | Urological                          | 6,220     | 17      | 32      |

Table 2. Logistical regression model summaries showing the significance of sexual orientation as a predictor of difference responses (note: includes only those significant at  $p < .05$ ; full results are provided as supplementary material and question numbers included for cross reference; see table footnote for key to model type).

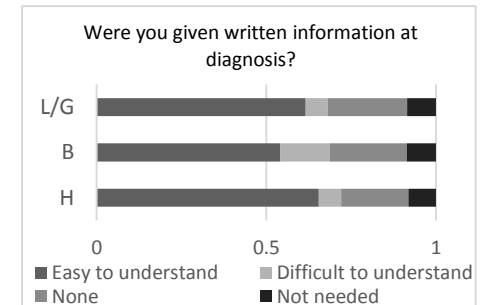
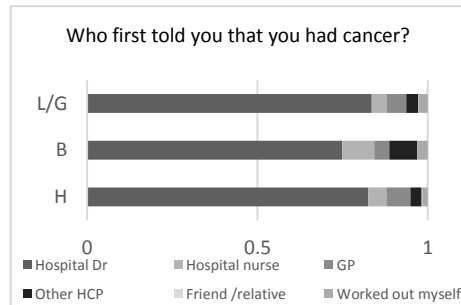
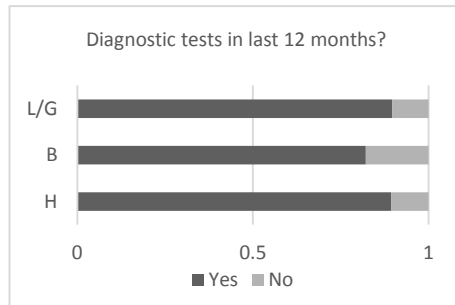
| Question  |  | Responses included in model (n) | Wald test results of sexual orientation as a predictor |       |
|---|--|---------------------------------|--|-------|
|   |  |                                 | $\chi^2$   | P     |
| Questions about cancer diagnosis                            |  |                                 |  |       |
|   | In the last 12 months have you had diagnostic test(s) for cancer at one of the hospitals named in the covering letter?           | 56295 <sup>1</sup>              | 7.19   | 0.03  |
|   | Who first told you that you had cancer?  | 57017 <sup>3</sup>              | 20.15  | 0.03  |
|   | When you were told you had cancer, were you given written information about the type of cancer you had?                          | 57465 <sup>3</sup>              | 17.48  | 0.01  |
| Questions about treatment decisions                         |  |                                 |  |       |
|   | Before your cancer treatment started, were you given a choice of different types of treatment?                                   | 55465 <sup>3</sup>              | 27.24  | <0.01 |
|   | Before you started your treatment, were you given written information about the side effects of treatment(s)?                    | 53176 <sup>3</sup>              | 13.93  | 0.01  |
|   | Were you involved as much as you wanted in decision about your care and treatment?   | 55404 <sup>2</sup>              | 11.50  | <0.01 |
| Questions about relationships with healthcare professionals |  |                                 |  |       |
|   | How easy is it for you to contact your nurse specialist?   | 48226 <sup>3</sup>              | 19.68  | <0.01 |
|   | When you have important questions to ask your clinical nurse specialist, how often do you get answers you can understand?        | 47050 <sup>3</sup>              | 18.17  | 0.01  |
|   | Did ward nurses talk in front of you as if you weren't there?  | 38696 <sup>2</sup>              | 8.31   | 0.02  |
|   | If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?               | 38936 <sup>3</sup>              | 63.59  | <0.01 |
| Questions about care after treatment had finished           |  |                                 |  |       |
|   | After leaving hospital, were you given enough care and help from health and social services?                                     | 38234 <sup>3</sup>              | 13.96  | 0.03  |
|   | Did hospital staff do everything possible to control the side effects of radiotherapy?   | 53839 <sup>3</sup>              | 15.68  | 0.05  |
|   | Have you been offered a written assessment and care plan?  | 48214 <sup>1</sup>              | 8.20   | 0.02  |
|   | Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home? | 38267 <sup>3</sup>              | 61.93  | <0.01 |
| Questions about psychosocial support and overall care       |  |                                 |  |       |

|  |   |                    |      |      |
|--|---|--------------------|------|------|
|  | Were you treated with dignity and respect by the doctors and nurses and other hospital staff?   | 38652 <sup>2</sup> | 8.53 | 0.01 |
|  | Sometimes people with cancer feel they are treated as “a set of symptoms” rather than a whole person. In your NHS care over the last year did you feel like that? | 56778 <sup>2</sup> | 9.55 | 0.01 |

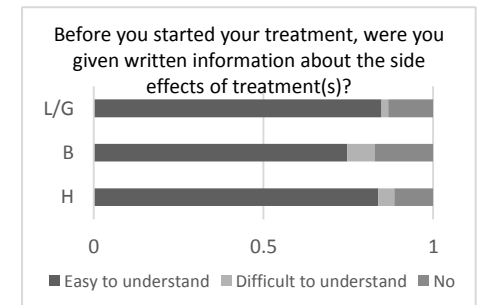
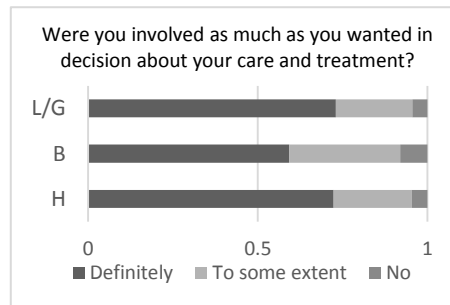
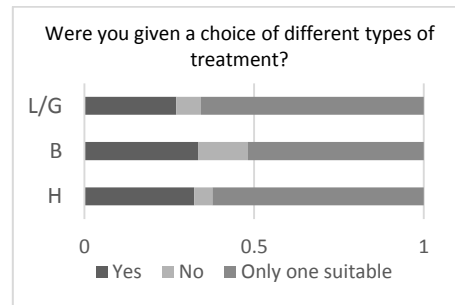
<sup>1</sup>logistic regression; <sup>2</sup>ordered logistic regression; <sup>3</sup>multinomial logistic regression

Figure 1. Between group comparisons in response likelihood for those questions reaching  $p < .01$  significance in Wald tests.

Questions about cancer diagnosis



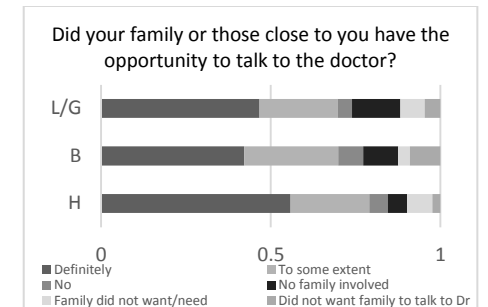
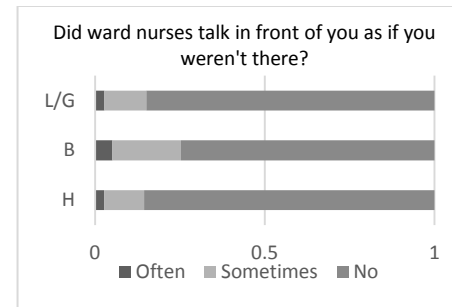
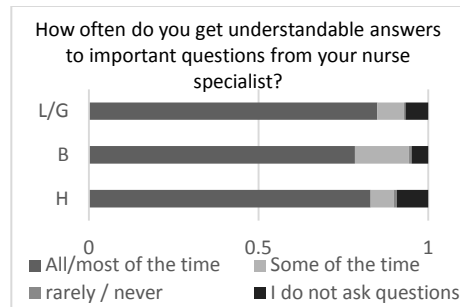
Questions about treatment decisions



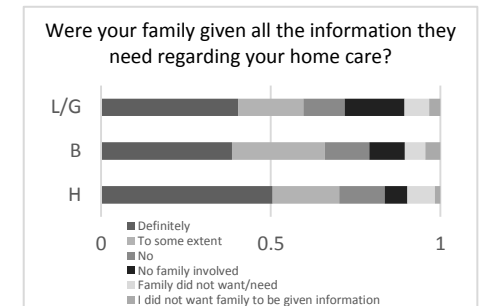
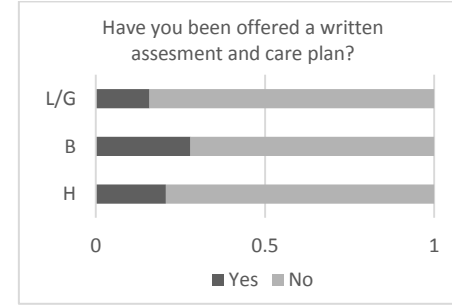
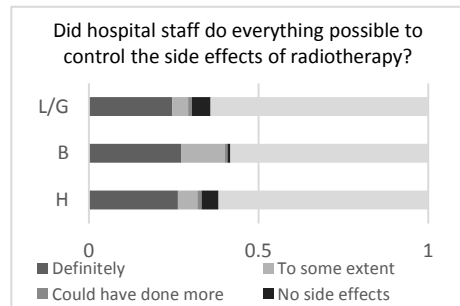
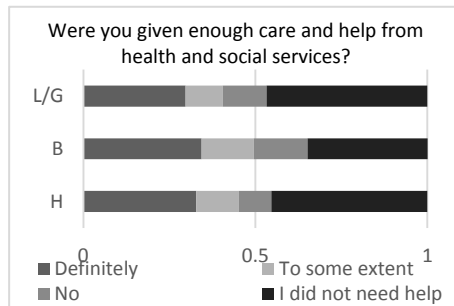


## Sexual orientation differences in cancer care

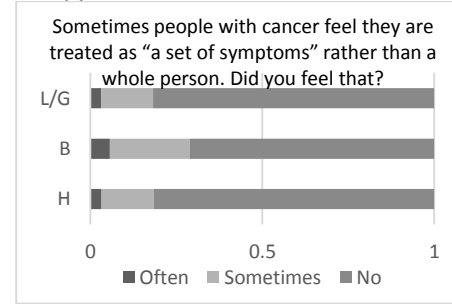
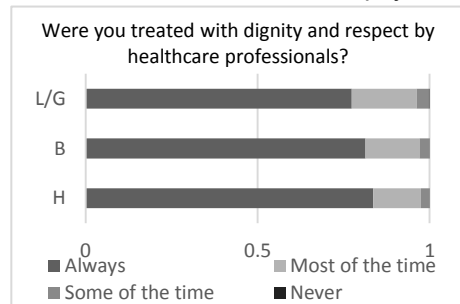
### Questions about relationships with healthcare professionals



### Questions about care after treatment had finished



### Questions about psychosocial support and overall care





Supplementary table: Results of statistical analysis of difference in response by sexual identity category for all questions in the patient experience survey.

| Question  | Responses included in model (n) | Model post estimation: Wald test results of sexuality (L/G, B, H) as a predictor |      |
|---|---------------------------------|--|------|
|   |                                 | $\chi^2$   | P    |
| 1: Before you were told you needed to go to the hospital about cancer, how many times did you see your GP (family doctor) about the health problem cause by cancer?         | 56044                           | 7.71   | 0.46 |
| 2: How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?   | 56656                           | 1.81   | 0.40 |
| 3: How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?   | 54978                           | 3.05   | 0.22 |
| 4: Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?                                   | 56551                           | 1.73   | 0.42 |
| 5: In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter? | 56295                           | 7.19   | 0.03 |
| 6: Beforehand, did a member of staff explain the purpose of the test?   | 50395                           | 11.31  | 0.08 |
| 7: Beforehand, did a member of staff explain what would be done during the test procedure(s)?   | 50629                           | 4.33   | 0.63 |
| 8: Beforehand, were you given written information about your test(s)?   | 47560                           | 2.82   | 0.83 |
| 9: Were the results of the test(s) explained in a way you could understand?   | 50598                           | 5.07   | 0.53 |
| 10: Who first told you that you had cancer?   | 57017                           | 20.15  | 0.03 |
| 11: When you were first told that you had cancer, had you been told you could bring a family member or friend with you?   | 54357                           | 8.32   | 0.22 |
| 12: How do you feel about the way you were told you had a cancer?   | 57397                           | 3.43   | 0.18 |
| 13: Did you understand the explanation of what was wrong with you?  | 57420                           | 2.09   | 0.72 |

|  |       |       |       |
|--|-------|-------|-------|
| 14: When you were told you had cancer, were you given written information about the type of cancer you had?  | 54765 | 17.48 | 0.01  |
| 15: Before your cancer treatment started, were you given a choice of different types of treatment?   | 55465 | 27.24 | <0.01 |
| 16: Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?          | 53934 | 4.67  | 0.59  |
| 17: Were the possible side effects of treatment(s) explained in a way you could understand?  | 56255 | 9.36  | 0.15  |
| 18: Before you started your treatment, were you given written information about the side effects of treatment(s)?  | 53176 | 13.93 | 0.01  |
| 19: Before you started your treatment, were you also told about any side effects of the treatment that could affect you in the future rather than straight away? | 53316 | 4.98  | 0.55  |
| 20: Were you involved as much as you wanted to be in decisions about your care and treatment?  | 55404 | 11.50 | <0.01 |
| 21: Were you given the name of a clinical nurse specialist who would be in charge of your care?  | 54857 | 3.04  | 0.22  |
| 22: How easy is it for you to contact your clinical nurse specialist?  | 48226 | 19.68 | <0.01 |
| 23: The last time you spoke to your clinical nurse specialist, did she/he listen carefully to you?   | 46682 | 3.45  | 0.18  |
| 24: When you have important questions to ask your clinical nurse specialist, how often do you get answers you can understand?                                    | 47050 | 18.17 | 0.01  |
| 25: Did hospital staff give you information about support or self-help groups for people with cancer?  | 54092 | 9.15  | 0.06  |
| 26: Did hospital staff discuss with you or give you information about the impact cancer could have on your work life or education?                               | 54447 | 5.62  | 0.23  |
| 27: Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?  | 54929 | 1.39  | 0.85  |
| 28: Did hospital staff tell you that you could get free prescriptions?   | 55643 | 6.96  | 0.14  |
| 29: Have you seen information (such as leaflets, posters, information screens etc.) about cancer research in your hospital?                                      | 56825 | 0.85  | 0.65  |
| 30: Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?  | 54107 | 0.40  | 0.82  |

|   |                     |       |       |
|---|---------------------|-------|-------|
| 31: If yes, did you then go on to take part in cancer research?   | 17284 <sup>1</sup>  | 3.21  | 0.20  |
| 32: During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?                | 57054               | 2.72  | 0.26  |
| 33: Before you had your operation, did a member of staff explain what would be done during the operation?   | 32373 <sup>2</sup>  | 2.11  | 0.91  |
| 34: Beforehand, were you given written information about your operation?  | 329866 <sup>2</sup> | 8.04  | 0.10  |
| 35: After the operation, did a member of staff explain how it had gone in a way you could understand?   | 32526 <sup>2</sup>  | 6.17  | 0.40  |
| 36: During the last 12 months, have you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter?                  | 57001               | 0.84  | 0.66  |
| 37: When you had important questions to ask a doctor, how often did you get answers that you could understand?  | 39030               | 9.37  | 0.15  |
| 38: Did you have confidence and trust in the doctors treating you?  | 39108               | 1.86  | 0.39  |
| 39: Did doctors talk in front of you as if you weren't there?   | 39037               | 4.83  | 0.09  |
| 40: If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?  | 38936               | 63.59 | <0.01 |
| 41: When you had important questions to ask a ward nurse, how often did you get answers you could understand?   | 38944               | 8.88  | 0.18  |
| 42: Did you have confidence and trust in the ward nurses treating you?  | 38989               | 0.20  | 0.91  |
| 43: Did ward nurses talk in front of you as if you weren't there?   | 38696               | 8.31  | 0.02  |
| 44: In your opinion, were there enough nurses on duty to care for you in hospital?  | 38720               | 2.33  | 0.31  |
| 45: While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?              | 38953               | 4.14  | 0.13  |
| 46: While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different? | 38881               | 2.75  | 0.25  |
| 47: While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?   | 38741               | 2.43  | 0.30  |
| 48: Were you given enough privacy when discussing you condition or treatment?   | 39045               | 2.84  | 0.24  |
| 49: Were you given enough privacy when being examined or treated?   | 39128               | 3.38  | 0.18  |
| 50: Were you able to discuss any worries or fears with staff during your hospital visit?  | 39028               | 12.37 | 0.14  |

|  |   |       |       |
|--|---|-------|-------|
| 51: Do you think the hospital staff did everything they could to help control your pain?   | 38553   | 9.19  | 0.16  |
| 52: Were you treated with respect and dignity by the doctors and nurses and other hospital staff?  | 38652   | 8.53  | 0.01  |
| 53: Were you given clear written information about what you should or should not do after leaving hospital?  | 38492   | 3.66  | 0.45  |
| 54: Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?  | 37464   | 0.09  | 0.96  |
| 55: Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?   | 38267   | 61.93 | <0.01 |
| 56: After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps, or physiotherapists)?                                      | 38234   | 13.96 | 0.03  |
| 57: Did hospital staff do everything possible to control the side effects of radiotherapy?   | 53839   | 15.68 | 0.05  |
| 58: Did hospital staff do everything possible to control the side effects of chemotherapy?   | 54769   | 5.08  | 0.75  |
| 59: While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?  | 54709   | 8.56  | 0.20  |
| 60: Whilst you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?   | 54759   | 1.59  | 0.95  |
| 61: In the last 12 months, have you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter?  | 56297   | 0.90  | 0.64  |
| 62: The last time you had an appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?  | 51896   | 0.32  | 0.85  |
| 63: As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?   | 46786   | 0.36  | 0.84  |
| 64: Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?  | 56348   | 2.96  | 0.81  |
| 65: Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care? | 54508   | 3.78  | 0.88  |
| 66: Have you had treatment from any of the following for your cancer? (tick all that   | <i>Not included in analysis of this dataset</i> |       |       |

|   |                                 |      |      |
|---|---------------------------------|------|------|
| apply)  | – see main text for explanation |      |      |
| 67: How much information were you given about your condition and treatment?   | 55973                           | 3.09 | 0.21 |
| 68: Have you been offered a written assessment and care plan? <i>A care plan is a document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional to help meet those goals.</i> | 48214                           | 8.20 | 0.02 |
| 69: Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year did you feel like that?   | 56778                           | 9.55 | 0.01 |
| 70: Overall, how would you rate your care.  | 57124                           | 3.59 | 0.17 |

<sup>1</sup> Lower response to this question because completion was only necessary where participants answered ‘yes’ to Q30.

<sup>2</sup> Lower response rates as participants were only invited to complete these questions if they had answered ‘yes’ to Q32.